

Mental Health Accessibility for Adults with Autism Spectrum Disorder: A Needs Assessment and Comparison of Services in Iowa and Puerto Rico

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Background:

Adults who have Autism Spectrum Disorder (ASD) have historically had difficulty with accessing mental health services. This project aims to take a closer look at the availability of mental health services in both Iowa and Puerto Rico, and then outline some of the barriers that exist for accessing services.

Objective:

- A. The trainees will be able to discuss the need for mental health services for adults who have an ASD diagnosis.
- B. The trainees will be able to discuss the availability of mental health services for adults who identify as having ASD.
 - a. In Iowa
 - b. In Puerto Rico
- C. The trainees will be able to discuss barriers that exist, both in Iowa and Puerto Rico, for adults who have ASD to obtain mental health services.
- D. The trainees will organize and analyze data collected from participant surveys using appropriate methods, with support from a research mentor.
- E. The trainees will design a survey that is built to be easily understood and accessible in a way that is best for people with ASD.

Method:

Our research team developed an instrument to assess the perceived availability and barriers for adults with ASD to access mental health services. The survey will be distributed to adults over the age of eighteen who have an ASD diagnosis and will be available in both English and in Spanish. The survey was developed using qualitative methodology and through a literature review. Adults with ASD and caregivers, both in Iowa and Puerto Rico, were interviewed using a semi-structured format. Iowa participants were recruited through The Autism Society of Iowa and included five adults with ASD and three caregivers. Participants from Puerto Rico were recruited through personal connections and included one adult with ASD and one caregiver.

Interviews were conducted through either ZOOM or in person and were approximately 20-30 minutes in length. Literature Review search terms included ASD, Mental Health and Adults. The survey was developed in English using information from the interviews and the literature review. It was then translated into Spanish by one of the team members and was entered into RedCap for distribution. The survey has been submitted to the University of Iowa Institutional Review Board (IRB) and is pending approval.

Results/Discussion:

The survey that our team developed contains a total of 26 questions, including demographic questions and takes approximately 10 minutes or less to complete/answer. The survey itself has many different accessible features. Within the survey, an individual can increase or decrease the font size, they can have it read to them in both English and Spanish by clicking on the speaker icon, and they can also change the language between English and Spanish by answering the first question, "Preferred Language."

Demographic Information:

- By 2011, the prevalence for ASD in children in Puerto Rico was between 4 and 17 years and was 0.9%. By 2016, reports showed a prevalence of 1.62% in children between 4 and 17 years. By 2023, most of these children would be adults, young adults, or transitioning into adulthood.
 - Average age for diagnosis 4.0 ± 1.3 years
 - 53 % of children with ASD were high functioning
 - 85% of males were considered as "level 2"
 - 14% of males were considered high functioning
 - Females were predominantly high functioning
- By 2017, studies in the US showed that the prevalence of ASD estimated to 2.21% of adults between 18-84 years.
 - Estimation of 0.86% prevalence in women 18-84 years old
 - Estimation of 3.62% prevalence in men 18-84 years old
 - At state level, the prevalence of ASD estimated at 2.28% of adults in Iowa
 - At state level, the prevalence of ASD estimated at 0.84% of women in Iowa
 - At state level, the prevalence of ASD estimated at 3.73% of men in Iowa

Key findings from Interviews:

Our research team is still waiting for IRB approval to distribute the survey. We ran into some unanticipated complexities with coordinating a project such as this between Iowa and Puerto Rico. However, we were able to develop the survey, and we will discuss the results that were gained from that process.

As we were developing our survey, it was recommended that we contact adults who had an ASD diagnosis and ask:

1. What were their mental health needs?
2. What barriers have they faced when accessing mental health services?
3. What has worked well regarding mental health services?
4. What type of survey would they be most likely to fill out?

We were able to meet with several individuals and support groups, both in Iowa and Puerto Rico. It was very powerful to discuss the issues of mental health as it has affected them personally. There were several themes that became apparent during our conversations regarding access to mental health services for adults with ASD.

- Finding providers that accepted their insurance was a significant concern. There were several individuals that had access to private insurance, which allowed greater relative access, however, for those that utilized Medicaid, they felt that they were at a great disadvantage.
- Second, finding providers that understood how to work with individuals who had an ASD diagnosis was a significant barrier. Several individuals shared that their own understanding and being able to label feelings and emotions is much different from that of a “neurotypical” individual.
- Transportation was a third theme that became apparent. Even if they were able to find providers that took their insurance and were willing/able to work with individuals with an ASD diagnosis, getting to them was a challenge. Specific reasons that were identified included: physical distance from the provider (several hours drive for some) and/or needing to rely on others for transportation.
- There is a gap in service availability when comparing children and adults. There is much more focus on children and their needs, but those children do grow up, and ASD does not go away. There needs to be more advocates for adults with ASD.

Our team also asked about what type of survey they would prefer to fill out. Answers to these questions led our team to change the type of survey that we were planning to develop.

- NO LIKERT SCALE! For the most part, this was very firmly stated. Several individuals noted that scales that had more than three (3) options were ambivalent and confusing.
- Please leave room for comments! Several individuals state that they would be more likely to answer Likert type scales if they could explain their answer.
- Keep it short and simple.

Key Findings from Literature Review:

ASD & Mental Health

- Most research has been on the child & adolescent years because ASD has been primarily considered to be a childhood diagnosis (Hollicks et al., 2018).

- Awareness of social challenges as compared to peers and appearing to be at greater risk for developing depression, low self-esteem, and anxiety when faced with peer rejection or bullying (Tse, J., et al., 2007).
- Adults with ASD were thought to be at increased risk for comorbid mental health conditions (anxiety & depression being more prominent) (Joshi et al., 2013)
- One important issue to consider is diagnostic over-shadowing (See Wood & Gallow, 2010)
 - This occurs when symptoms/behaviors that are common to a diagnosis mirror that of another diagnosis, and are then attributed to only one (i.e., reduced social interactions of a person with ASD may not appear as a red flag for depression because it is expected symptomatology in ASD)
- ADHD, Anxiety Disorders, Sleep-wake disorders, disruptive behavior disorders & depressive disorders are the most common mental health problems among autistic individuals (Lai, M. et al, 2019).
- Co-occurring psychiatric conditions noted to be risk factors for suicide attempts & deaths (Kolves, K., et al., 2021)
- Pool lifetime current/lifetime prevalence for adults with anxiety is (27%/42%) (Hollicks et al., 2018).
 - The study offers data on pool current/lifetime prevalence rates for the following specific types of anxiety:
 - Social Phobia (29%/20%)
 - OCD (24%/22%)
 - GAD (18%/26%)
 - Panic/agoraphobia (15%/18%)
 - Specific Phobia (6%/31%)
 - PTSD (1%/5%)
 - Separation Anxiety (3%/21%)
- Pool lifetime current/lifetime prevalence for adults with depression is (23%/27%) (Hollicks et al., 2018).

ASD & Mental Health Services

- Examples of mental health services include: (diagnostic evaluation, individual/group/family psychotherapy, case management, testing evaluation, crisis intervention & consultation) (Maddox, et al, 2021).
- Examples of mental health service providers include: (psychologists, masters-level therapists, social workers, psychiatrists, psychiatric nurses, primary care physician's & other allied health professionals) (Maddox, et al, 2021).
- Increased rates of suicidal thoughts & behaviors (Cassidy, S., 2020)
- Co-occurring psychiatric conditions noted to be risk factors for suicide attempts & deaths (Kolves, K., et al., 2021)

- Important to tailor EBI (evidence-based interventions) to the unique characteristics of autistic individuals (increasing caregiver involvement, adding visual supports, incorporating focused interests, using more concrete language). (Dickson, K.S., 2021).
- Limited community workforce capacity is another major barrier to accessible mental health services for autistic individuals (Maddox, B.B., et al., 2020; Adams, D. & Young, K., 2020; Camm-Crosbie, L. et al., 2019)
- Complex & disconnected systems with multiple service points that are not always well connected (Maddox, et al, 2021).
- Racial/ethnic/SES disparities: (Schott, W., et al., 2021)) found that Black autistic adults had significantly greater unmet needs for mental health services.

Survey Access:

Please only look through the survey. We plan to send this out and collect data after LEND and IRB Approval. Thank you!

<https://redcap.icts.uiowa.edu/redcap/surveys/?s=K9P78FTCYMFXF8HY>

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